IIHUK
Idiopathic Intracranial Hypertension

“I felt so, so alone, joined the Hope Programme and realised... I wasn’t”

Report: A multi-method evaluation of the long-term mental wellbeing outcomes of a peer-supported digital self-management programme for people living with Idiopathic Intracranial Hypertension

May 2026

the hope programme

Acknowledgments

We would like to thank everyone who contributed to this evaluation of the Hope Programme for IIH.

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Report title

Evaluating the long-term mental wellbeing outcomes and acceptability of a peer-supported digital self-management programme for people living with Idiopathic Intracranial Hypertension: A multi-method evaluation: *“I felt so, so alone, joined the Hope Programme and realised... I wasn’t”:*

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About this report

This report presents findings from an evaluation of the Hope Programme for people living with Idiopathic Intracranial Hypertension, also known as IIH. The evaluation explored whether the programme was acceptable to participants and whether improvements in mental wellbeing were sustained over time.

The Hope Programme for IIH was developed and delivered through a partnership between IIH UK and Hope 4 The Community CIC. The programme provides digital, peer-supported self-management support for people affected by IIH.

The evaluation was funded by an IIH UK research grant 2024.

About IIH UK

IIH UK is a national charity supporting people living with Idiopathic Intracranial Hypertension. IIH is a rare neurological condition caused by raised pressure around the brain. It can cause severe headaches, visual symptoms, fatigue, tinnitus, cognitive difficulties and, in some cases, permanent sight loss if not treated promptly.

IIH UK provides information, support and community for people living with IIH, as well as parents, carers and families. The charity also raises awareness of IIH, supports research and works to improve understanding of the condition among healthcare professionals, services and the wider public.

About Hope 4 The Community CIC

Hope 4 The Community CIC (H4C) is a social enterprise that develops, delivers and evaluates self-management courses for people living with long-term conditions.

H4C works with charities, healthcare organisations, universities and people with lived experience to create evidence-based programmes that support wellbeing, self-management, confidence and peer connection. H4C's programmes are designed to complement clinical care by addressing the emotional, social and practical impact of living with or looking after someone with physical and mental health long-term conditions.

About the Hope Programme

The Hope Programme is a range of self-management courses based on positive psychology, mindfulness and cognitive behavioural therapy, built on 25 years of research evidence at Coventry University. The programme targets people living with long-term conditions and carers, empowering them to take control of their health and wellbeing. Over 36,000 people have benefited from the Hope Programme to date. Several studies have shown that the Hope Programme improves positive mental wellbeing, confidence to manage, gratitude and hope whilst also reducing depression and anxiety. Improving quality of life and patient activation thus reducing the burden on healthcare services.

Executive summary

IIH UK research grant 2024: Does the Hope Programme for Idiopathic Intracranial Hypertension have a long-term impact on mental wellbeing?

Purpose

This report summarises the key findings from an evaluation of the Hope Programme for Idiopathic Intracranial Hypertension, a six-session digital, peer-supported self-management intervention delivered in partnership between IIH UK and Hope 4 The Community CIC. IIH is a condition associated with significant psychological distress and unmet need for holistic self-management support. The Hope Programme provides evidence-based self-management tools, emotional and psychological support, and peer connection. The purpose of this evaluation was to assess the long-term mental wellbeing of participants attending the Hope Programme and to determine whether it was acceptable to people living with IIH.

Methods

The evaluation used a pragmatic, multi-method design across 11 Hope Programmes delivered between 2022 and 2025. Of the 454 participants who enrolled, 83 participants completed a mental wellbeing measure during the six-week intervention, and 41 participants completed the mental wellbeing measure at long-term follow-up. Mental wellbeing was measured using the *Short Warwick-Edinburgh Mental Wellbeing Scale* (SWEMWBS) at four timepoints: the start of the programme, Session 1 (T1), mid-programme, Session 3 (T2), programme completion (Session 6, T3), and long-term follow-up (T4) from 12 to 50 months later. A one-way repeated measure (ANOVA), with Bonferroni correction for multiple testing, was performed to explore changes over time between T1, T2, T3 and T4. The level of statistical significance was set at P=0.05. Qualitative data explored participant experience and programme acceptability through interviews and written feedback from 16 participants. Acceptability was analysed using the Theoretical Framework of Acceptability.

Main findings

Mental wellbeing

At enrolment, the mean wellbeing score was 18.2, which is indicative of low mental wellbeing and nearly three-quarters of participants (73%) were classified as probably/possibly depressed/anxious. Across the four time points, there was a statistically significant improvement ($F(3,120)=6.1$, $p<.001$) in wellbeing, with scores increasing from 18.2 (start of the Hope Programme) to 19.6 (mid-programme), 20.4 (completion of programme) and 19.7 at long-term follow-up. There was a significant effect of time on mental wellbeing across the four measurement points. Scores at mid-programme, completion, and follow-up were all significantly higher than at baseline, and the long-term follow-up scores suggest that gains were largely maintained over time. The proportion of participants who were "probably/possibly" depressed/anxious fell from 73% at the start to 56% at programme completion, increasing to 61% at 12-50 months long-term follow-up.

Acceptability

Participants experienced poor and stigmatising communication at diagnosis, limited guidance, and a lack of holistic and psychological support in clinical care. Many participants joined the Hope Programme for information, peer support, and strategies for coping. Many participants reported that the Hope Programme helped them feel less alone. Many described the value of meeting others living with IIH, learning how to pace themselves, manage stress, set realistic goals, and practice self-compassion and acceptance. Participants described positive emotions such as hope and peace. They valued the respectful and non-judgemental

approach to sensitive topics like weight and found the programme to be flexible to fit around work, caring roles and fluctuating symptoms. Several participants reported that the programme helped them cope better with work, family life, clinical appointments.

Suggestions for improvement

There were several areas where participants felt the Hope Programme could be improved:

- Some participants experienced visual strain, screen fatigue or cognitive burden, particularly when symptoms were severe, and suggested reducing the amount of written material and providing more audio-based content (e.g. podcasts).
- Live Hope Cafés (virtual group sessions on Zoom) were valued by some participants, but attendance was challenging during working hours, and they recommended more flexible scheduling (e.g. evening sessions).
- Participants suggested more content and training on self-advocacy in medical consultations and navigating the healthcare system.

Limitations

This was a real-world, pragmatic evaluation rather than a controlled trial, so the findings should be interpreted cautiously. Improvements in mental wellbeing cannot be attributed solely to the Hope Programme. There was no control group and follow-up mental wellbeing data were provided by participants who attended all six sessions. Nearly all the participants were women and white. While this may partly reflect the IIH population, it limits the generalisability of the findings to more diverse groups of people living with IIH.

Recommendations

Based on the findings, there is a case for continuing delivery of the Hope Programme and for ongoing larger controlled evaluations.

1. Given the high levels of acceptability and preliminary evidence of improvements in long-term mental wellbeing, continue delivery of the Hope Programme as a core part of IIH UK's support offer.
2. Refine content and accessibility, including more audio content, review of content volume, and flexible scheduling for live elements.
3. Strengthen healthcare-navigation content, particularly self-advocacy, communication with clinicians, and support around difficult healthcare experiences.
4. Explore ways to widening reach to more diverse groups and exploring how the Hope Programme can be adapted or targeted to address inequalities in access and outcomes.
5. Use these findings to support further delivery and research funding applications and use a clinical and cost-effectiveness randomised controlled trial design.

Conclusion

The Hope Programme is acceptable to people living with IIH and has the potential to improve mental wellbeing in the short and long-term. The Hope Programme helped participants feel less isolated, more informed, and better able to cope. The preliminary evidence reported here warrants further development of the intervention, wider implementation and a more robust evaluation.

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Introduction

Idiopathic Intracranial Hypertension (IIH) is a rare, neurometabolic condition characterised by raised intracranial pressure. Clinical features include chronic headache, papilledema, transient visual obscuration and, in severe cases, permanent visual impairment (Mollan et al., 2018). Although the exact causes of this condition remain unknown it occurs more often in women of childbearing age compared with men and children as well as in people who are overweight or obese (Mollan et al., 2016).

In England, incidence of IIH rose between 2002 and 2016 from 2.3 to 4.7 per 100,000 in the general population and was more common in those living in areas of social deprivation (Mollan et al., 2019a). In addition to neurological symptoms, people living with IIH can experience a significant psychosocial burden. A large survey-based study of people with IIH found that 56% met criteria for depression on the Major Depression Inventory (Witry et al., 2021). A recent UK cohort study involving over 3,000 women with IIH found that they have a substantially higher risk of depression and anxiety than the general population (Mollan et al., 2023).

Consensus guidelines recommend the need for support to deal with the psychological burden of living with IIH (Mollan et al., 2018). However, structured, evidence-based holistic mental health interventions are scarce.

In 2021, a partnership between IIH UK and Hope 4 The Community CIC, supported by National Lottery Community Fund grant funding, led to the co-design, development and commissioning of the first self-management HOPE (Help Overcome Problems Effectively) Programme for people living with IIH.

Since its launch in March 2022, over 800 participants have been reached across all IIH Hope Programmes, including parents of children with IIH, with delivery funded entirely by IIH UK. This study focuses on 454 of these participants who enrolled in 11 courses for people living with IIH delivered between 2022 and 2025.

An unpublished programme evaluation demonstrated meaningful end of course improvements in mental wellbeing (mean increase ≥1 point, *Short Warwick-Edinburgh Mental Wellbeing Scale* (SWEMWBS). The present study evaluates its long-term impact.

Many digital health companies do not research the development and effectiveness of their tools, which can result in the roll out of interventions that are not evidence-based or effective (Fitzpatrick et al., 2024). Academic-industry partnerships are a way towards ensuring that products are evidence-based, safe and effective. However, these studies are often conducted in highly controlled research environments rather than in real-world environments. To ensure external validity, it is important to evaluate digital interventions within typical, real-world, delivery conditions. This is what we attempted to achieve in this study.

Research questions:

1. *What long-term impact does a digital self-management intervention have on the mental wellbeing of people living with IIH?*

2. *Is the Hope Programme acceptable for people living with IIH?*

The Hope Programme for IIH

The Hope Programme is a digital self-management intervention delivered via a digital platform *powered by H4C* developed by Hope 4 The Community CIC (H4C) social

enterprise. The Hope Programme is grounded in positive psychology, cognitive behavioural therapy (CBT) and self-management principles. The Hope Programme adopts an innovative approach to self-management because it encourages positive psychological and behavioural change by fostering positive psychological emotional states and builds on participants' existing strengths and resiliencies, rather than focusing predominantly on skills' deficits. Our qualitative evaluations (Horton et al., 2026; Percy et al., 2024) have shown that instillation of hope, universality (realising you are not alone), altruism, are key active ingredients of self-management programmes, which Yalom (2005) has described as "therapeutic curative factors." Participants observe each other and the facilitators successfully overcoming the challenges of living with a long-term condition through achieving their weekly goals (instillation of hope), share common experiences (universality) and are encouraged to support each other through the provision of informational and emotional support (altruism). Karwoski et al., (2006) suggest that there is considerable conceptual and technical overlap between CBT and positive psychological approaches, which are included on the Hope Programme including: developing a therapeutic relationship between participant and facilitator, goal setting, cognitive restructuring, mindfulness, scheduling pleasant activities, identifying and reviewing successes, monitoring mood, relaxation training, and problem-solving. The Hope Programme promotes an upward spiral of positive emotions to improve wellbeing and coping (Fredrickson, 2001). Developing hope and gratitude, which are two important concepts in positive psychology, are core concepts on the Hope Programme.

The Hope Programme for IIH shares the same theoretical frameworks as the original Hope Programme. The IIH specific content was co-created with 11 adults living with Idiopathic Intracranial Hypertension (IIH) and 6 healthcare professionals (IIH co-creation report is available upon request from H4C). The intervention was facilitated by trained peers with lived experience of IIH and delivered in a group format for up to 60 participants. The intervention followed a structured six-session format delivered over six weeks, with one module released for a week and designed to take approximately 2 hours to complete at the participants' own pace. Modules combined IIH-specific information (e.g., understanding raised intracranial pressure, pacing and energy management, communicating effectively with clinicians), audio-visual content, interactive cognitive-behavioural exercises, and evidence-based, self-management activities (See Figure 1 and Table 1 for Session content).

Figure 1 Hope Programme for IIH session content overview

Table 1 Hope Programme for IIH session content (detail)

Session 1: Instilling Hope This session introduces participants to the Hope Programme, the Hope Cafés and the IIH journey. It covers IIH basics, positivity, gratitude, self-compassion and goal setting. Participants reflect on how they view their health, hear IIH stories, practise relaxed breathing and set a personal goal.
Session 2: Stress management, acceptance and compassion This session explores stress management, unhelpful thinking styles and ways to unstick from difficult thoughts. Participants learn about acceptance, compassion and kindness, hear Diana's story, practise the Thought leaves activity and set a personal goal.
Session 3: Managing IIH symptoms, fatigue and mindfulness This session focuses on IIH symptoms, including headaches and fatigue. Participants use tools such as a symptom tracker, fatigue diary and pacing diary, and learn about boom and bust patterns, mindfulness, the 3 Ps, life priorities and sleep. The session includes a mindfulness meditation and goal setting.
Session 4: Managing setbacks and communication This session supports participants to manage setbacks, make setback plans and prepare for concerns about the future. It covers vision and IIH, communication skills, accepting help and talking with friends, family, healthcare professionals, employers or educators. Activities include compassion for worries, preparing for a healthcare visit, gratitude and goal setting.
Session 5: Your body, getting active, creative and eating well This session explores IIH and weight, body changes, sexuality, identity and intimacy. It also covers getting active, the IIH Activity Programme, eating well, creativity and hopes for the future. Participants hear Mellissa's story and complete activities including a 3-minute breathing space, happiness pie and goal setting.
Session 6: Moving forward with Hope This session helps participants reflect on their progress and plan how to stay hopeful after the programme. It covers authentic happiness, hope, character strengths, using strengths in everyday life and reviewing the Hope Programme. Participants complete wellbeing and health reflections, share feedback and are encouraged to stay hopeful.

The intervention is hosted on H4C's digital platform, *powered by H4C*. The content comprises text, images, videos, downloadable documents, and interactive activities (e.g., quizzes, self-monitoring tools, and diaries). Figure 2 shows the visuals of the Hope Programme when used on a smartphone. The intervention has been approved by the Quality Institute for Self-Management Education and Training for the provision of self-management structured education and certified by the Organisation for the Review of Care and Health Apps, indicating compliance with best practice in data security, professional assurance, usability, and accessibility.

Figure 2 visuals of the Hope Programme for IIH when used on a phone

Discussion forums enabled peer interaction and shared experience. Once accessed and viewed, the content can be viewed offline, reducing the need for a data plan or high-quality internet connection. Live Hope Cafés (45-minute virtual group sessions on Zoom at set times), facilitated by IIH UK facilitators, are run to offer deeper connection to those who would like to meet people directly.

The facilitator's role is to offer support to participants, encourage discussion in forums by inviting participants to respond with comments to specific questions, or respond to questions/comments posted by participants. Facilitators also monitor daily posts for safety and monitor participation within the group and report any technical problems to H4C technical support team. Facilitators typically spend around 1 hour per working day (30 hours across 6 weeks) supporting participants. Intervention fidelity is supported through facilitator training, toolkits, and monitoring of engagement metrics.

During the programme, participants have the option in Session 1, 3 and 6 to complete a short mental wellbeing outcome measure, the *Short Warwick-Edinburgh Mental Wellbeing Scale* (SWEMWBS) which they can use to self-monitor their mental wellbeing throughout. Scores are fed back to participants to indicate the level (low, average or high) of their mental wellbeing and are recommended a range of support materials and sources from self-management techniques through to contacting a healthcare provider such as their GP or mental health services.

Methods

Study design

The study followed a pragmatic, multi-method design, using descriptive quantitative engagement and adherence data, longitudinal mental wellbeing outcome data and qualitative and text-based course experience data.

Process

Quantitative data

User engagement

Participants' intervention *adherence and engagement* data was automatically captured by the *powered by H4C* platform and was drawn from Hope Programme's delivered between 2021 and 2025.

Mental wellbeing

Participants who had completed the mental wellbeing scale (SWEMWBS) while on one of the 11 Hope Programmes at all 3 timepoints (Session 1 (T1), Session 3 (T2) and Session 6 (T3) and who had completed at least 3 sessions (classified as "completers"), were contacted between 12 months to 50 months (T4) after they had finished the Hope Programme. Participants were contacted via email containing a link to a follow-up questionnaire hosted by Qualtrics and to complete the SWEMWBS mental wellbeing scale and share their experience of the Hope Programme. Participants also indicated whether they would be prepared to take part in an interview about their experiences of attending the Hope Programme.

Quantitative *mental wellbeing* data was captured by the Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS) (Stewart-Brown et al., 2009), which was embedded within the Hope Programme in Sessions 1, 3, and 6. The SWEMWBS is a 7-item scale measuring positive mental wellbeing in adults. Items ask participants to indicate how often over the past two weeks they have experienced positive feelings and functioning, including statements such as "I've been feeling optimistic about the future" and "I've been dealing with problems well." Each item is rated on a 5-point Likert scale (1 = none of the time, 2 = rarely, 3 = some of the time, 4 = often, 5 = all of the time), producing a total raw score ranging from 7 to 35, with higher scores indicating greater positive mental wellbeing. A change of one point or more has been identified as a meaningful change at a group level (Shah et al., 2018). The total raw scores were converted to metric scores (Stewart-Brown et al., 2009). Scores of 18 or less correspond to *probable* depression or anxiety, 18-20 *possible* depression or anxiety and scores of 20 or more correspond to scores in *well* groups (Shah et al., 2021).

Analysis

Sociodemographic characteristics, engagement and outcome data are presented descriptively such as means, frequencies and standard deviations (SDs). A one-way repeated measure (ANOVA), with Bonferroni correction for multiple testing, was performed to explore changes over time between T1, T2, T3 and T4. All analyses were performed using IBM SPSS (Version 31). The level of statistical significance was set at P=0.05.

Qualitative data

We assessed the acceptability of the Hope Programme by qualitative interviews with participants who had completed at least 3 sessions of the Hope Programme ("completers"). Fifteen participants who completed the Hope Programme and the follow-up T4 questionnaire, expressed an interest in taking part in interviews and seven were interviewed. Three participants, who were unable to take part in the interviews due to scheduling issues agreed to provide written responses via Qualtrics. Six participants who did less than 3 sessions ("non-completers") also provided written responses via Qualtrics.

The seven participants who were interviewed took part in an individual Zoom recorded interview, lasting between 27 minutes and 48 minutes (average 38 minutes). Interview data were automatically transcribed and downloaded from Zoom. Individual audio-recorded semi-structured telephone interviews were conducted by a trained qualitative researcher with experience of conducting qualitative research with people living with long-term conditions. At the beginning of each interview, the interviewer introduced herself and explained the purpose of the research: to explore participants' experiences of the programme and gather views to support future improvement. Interviews explored participants' reasons for taking part in the programme, experiences of the programme content, tools, and format, any changes in self-management or wellbeing attributed to the programme, and suggestions for future iterations.

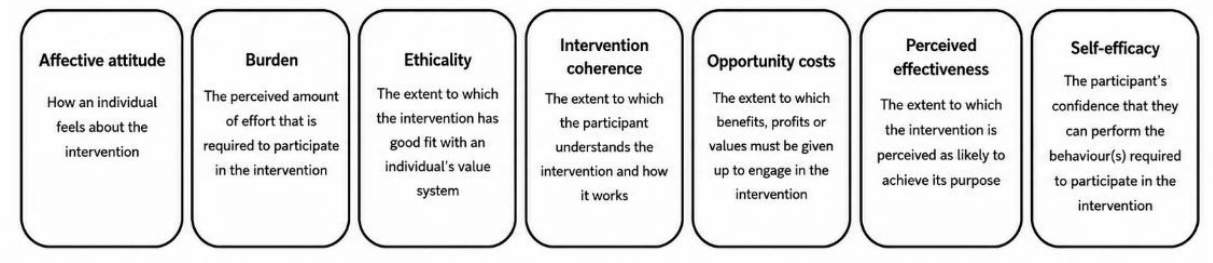
In one of our previous long-term follow studies participants were able to describe in depth their experiences of attending a self-management intervention they had attended 8 years previously (Barlow et al., 2009). Such recall has been linked to emotionally salient events (Pashler, 2002). Nevertheless, a content slide summarising programme sessions was available to share on screen to support recall, given that several participants had completed the programme some years previously. Interviews were audio-recorded with participants' consent secured verbally at the start of the interview**.** Interview transcripts were anonymised, and participants are referred to by participant number throughout (P1–P7). Participants were contacted via email containing a link to a follow-up questionnaire hosted by Qualtrics and to share their experience of the Hope Programme.

Analysis

Theoretical Framework of Acceptability (TFA)

This study used the Theoretical Framework of Acceptability (TFA) (Sekhon et al., 2017). The TFA was developed to assess how relevant and acceptable an intervention is perceived to be by participants. This framework has been widely applied in health interventions, to identify factors influencing both acceptability and engagement (Sekhon et al., 2017, 2022). The information gained from applying the TFA helps researchers understand how different components of an intervention are experienced and which aspects may support or hinder its implementation (Sekhon et al., 2022). Figure 3 shows the seven TFA domains and a brief description of each domain.

Figure 3 Theoretical Framework of Acceptability and its seven domains



These domains provided a structured but flexible foundation for developing prompts that could encourage participants to share their experiences about the intervention. Although each domain stands alone, in practice, they interact and influence the experiences overall (Sekhon et al., 2017). The TFA is relevant because it supports this study's aim by enabling a comprehensive exploration of multiple acceptability domains (Sekhon et al., 2017). The TFA is useful because it captures the multidimensional nature of acceptability, enabling a more comprehensive understanding of how and why an intervention may be perceived as acceptable or not.

The interview schedule

The interviews were guided by the TFA. For example, for the *Affective* domain, participants were asked: "*Overall, what are your feelings or reactions to the Hope Programme. What aspects, if any, did you particularly like or dislike*." For the *Effectiveness* domain, participants were asked *"Were there particular modules, tools, or exercises that you found especially helpful or unhelpful?*" The participants were also asked about their reasons for joining the Hope Programme and their recommendations for improving the intervention. The interview schedule is available in the Appendix 1. Participants received a minimum of £25 voucher compensation for their involvement.

Thematic analysis was employed to identify, analyse, and report themes within the data (Braun and Clarke 2006). This study employed a hybrid process of inductive and deductive coding. The deductive coding scheme was used in line with each domain of the TFA. Any findings that were relevant to the research aim but not relevant to the TFA domains were coded inductively and separated into different themes. This study investigated retrospective acceptability. The lead researcher (AT) conducted the initial coding, which was then reviewed by another member of the research team (BA). The research team engaged in discussions and comparisons to ensure agreement on the codes for the TFA domains. The transcripts were not returned to the participants for verification or feedback. Inclusion of a series of 3 dots (…) in the quotes are used to indicate parts of sentences omitted to aid with the clarity and brevity of the findings. The quotes presented below are chosen as the most salient and relevant to the TFA domains. Additional quotes for each domain are also presented in Appendix 2. Completer participants who took part in the interview are identified as P1 to P7; P8 to P10 are completer participants who responded to the questionnaire and P11 to P16 are non-completer participants.

Findings

Four hundred and fifty-four participants enrolled in 11 Hope Programmes between 2022-2025. Of these, 83 completed Session 1 (T1), 3 (T2) and 6 (T3) SWEMWBS and were contacted by H4C and sent a Qualtrics survey, which included the long-term follow-up (T4) mental wellbeing scale (SWEMWBS) to complete. Forty-one participants completed the T4 mental wellbeing scale. Table 2 shows the sociodemographic characteristics of the 41 participants who completed the SWEMWBS at all 4 timepoints.

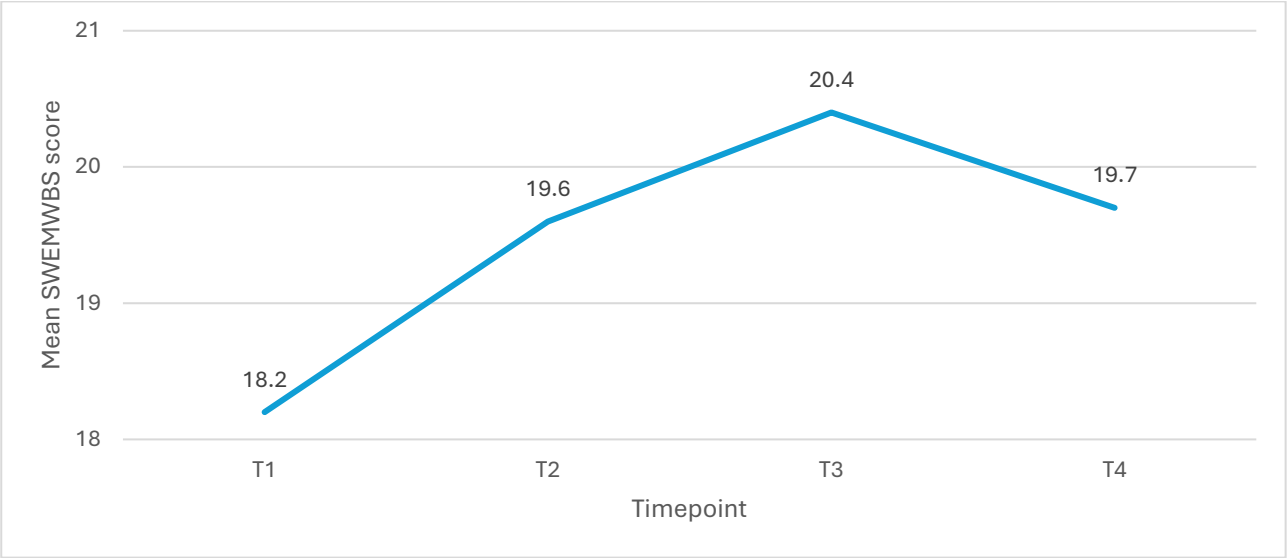
Table 2 shows that of the 41 participants, all (100%) were white, majority (98%) were female, the mean age was 42 years, and over a third (38%) lived in the lowest three indices of deprivation (IMD) deciles. All participants (100%) attended at least 3 sessions of the Hope Programme. At the start of the intervention the mental wellbeing mean score was 18.2 (standard deviation, 3.4). Nearly three quarters of all participants (30/41, 73%) were classified as “probably/possibly depressed/anxious” (SWEMWBS scores <20). These characteristics are similar to the larger sample participants (n=454) who started the Hope Programme. The main difference is in the sessions attended category, where 76% (344/454) of participants attended at least 3 sessions.

Table 2 Sociodemographic characteristics and Session 1 (T1) mental wellbeing scores for total long-term follow-up participants (n=41)

Demographics and mental wellbeing	Long-term follow-up group (n=41)
Age - years, Mean (min, max)	42 (22-68)
Gender (Female %)	98%
Ethnicity (White %)	100%
IMD: Lowest 3 deciles %)	38%
Completed at least 3 sessions (%)	100%
Probable/possible depression/anxiety (%)	73%
Mental wellbeing (Mean, (SD))	18.2 (3.4)

There was a significant effect of time on mental wellbeing across the four measurement points, $F(3,120)=6.1$, $p<.001$. Mental wellbeing scores at T2 ($M = 19.6$, $SD = 3.3$), T3 ($M = 20.4$, $SD = 4.0$) and T4 ($M = 19.7$ $SD = 3.7$) were all higher than T1 ($M = 18.2$, $SD = 3.4$) ($p = .025$ T1 and T2 difference; $p<.001$ T1 and T3 difference; and $p = .05$ T1 and T4 difference). Mental wellbeing scores at T2, T3 and T4 did not differ significantly from each other ($p > .750$). Mental wellbeing increased significantly from baseline and remained higher at all subsequent time points, with the largest gain evident by time 3 and no statistically reliable differences between T2, T3 and T4. See Figure 4.

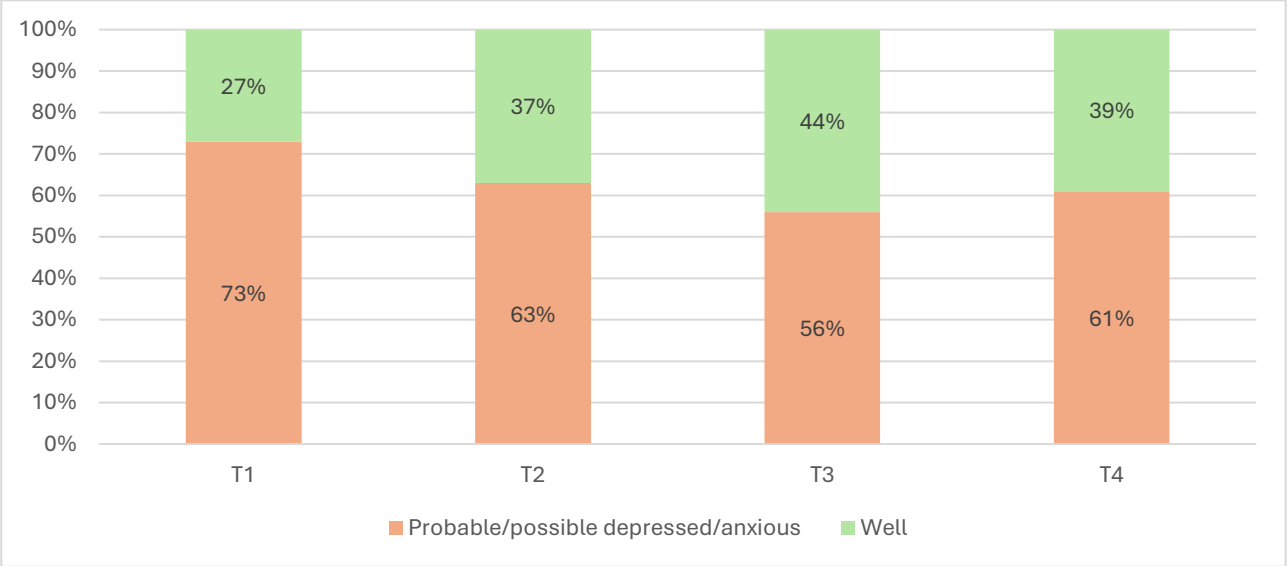
Figure 4 Mean Mental wellbeing scores over four timepoints (n=41)



Over time the proportion of participants classed as probable/possible depressed/anxious (SWEMWBS scores <20), *decreased* between T1 and the other three timepoints: (30/41,73%), T2 (26/41,63%), T3 (23/41,56%), and T4 (25/41,61%).

The proportion of well participants (SWEMWBS scores of >20) *increased* between T1 and the other three timepoints: (11/41,27%), T2 (15/41,37%), T3 (18/41,44%), and T4 (16/41,39%). See Figure 5.

Figure 5 Proportion of participants classed as probable/possible depressed/anxious or well over four time points (n=41)



Hope Programme acceptability findings

Table 3 shows that all the participants who provided feedback about their experiences of the Hope Programme identified as female, with a mean age of participants was 38 years (range 26 to 55 years). Over a quarter (27% 4/15, IMD data were missing for one participant) lived in the lowest 3 IMD deciles. The mean time in months since attending the Hope Programme was 29 months (range 7 to 49 months). At the start of the intervention the mean mental wellbeing score for the 14 participants who completed the SWEMBS in Session 1, was 18.9. All participants were white. Participants P1 to P10 (completers) attended all six sessions and participants P11 to P16 (non-completers) attended 1-2 sessions.

Table 3 Characteristics of participants (N=16)

ID	Interview/ questionnaire	Time since attending (months)	Age	Sessions attended	IMD	SWEMWBS Session 1
P1	I	43	33	6	6	16.4
P2	I	47	30	6	7	19.9
P3	I	25	43	6	1	18.5
P4	I	25	48	6	3	20.7
P5	I	43	55	6	4	20.7
P6	I	49	43	6	1	19.3
P7	I	25	27	6	9	19.3
P8	Q	25	31	6	10	14.8
P9	Q	49	40	6	4	24.1
P10	Q	49	47	6	8	16.3
P11	Q	13	34	2	10	15.9
P12	Q	7	26	2	5	17.4
P13	Q	43	49	1	9	21.5
P14	Q	13	20	1	-	-
P15	Q	7	43	2	5	19.3
P16	Q	7	34	2	1	-

Table 4 shows the thematic domain themes and subthemes.

Table 4 Thematic domain themes and subthemes

Domain	Subthemes
Reasons for joining	• Poor communication at diagnosis and unmet information needs • Seeking connection • Usefulness of a digital format Learning self-management tools and regaining control
TFA domain	**Subthemes**
Affective attitude: The affective response of an individual towards the intervention	• Relief, hope and peace • Inspiration • Disappointment
Burden: The perceived amount of effort that is required to engage in the intervention"	• Low overall burden and flexible • Cognitive and emotional burden • Volume of content
Ethicality: The extent to which the intervention has good fit with an individual's value system	• Respectful and non-judgemental discussion of weight and lifestyle • Emphasis on self-compassion, boundaries and acceptance
Intervention coherence: The extent to which the participant understands the intervention and how it works	• Understanding the overall purpose and scope of the programme • Clarity about how specific tools work
Opportunity costs: The extent to which benefits, profits or values must be given up to engage in the intervention	• Reallocating discretionary time rather than giving up valued activities • Higher opportunity costs for synchronous elements (Hope Cafés)
Perceived effectiveness: The extent to which the intervention is perceived as likely to achieve its purpose	• Understanding IIH and feeling less alone • Psychological coping and broader life impacts • Use of self-management techniques • Peer support and validation
Self-efficacy: The participant's confidence that they can perform the behaviour (s) required to participate in the intervention	• Confidence in completing the programme • More personalised, engaging information and activities • Symptom-related reasons for stopping using self-management tools

Reasons for joining the Hope Programme

Poor communication at diagnosis and unmet information needs

Participants joined the Hope Programme in response to gaps in how IIH information was presented within clinical care. Poor communication at diagnosis caused confusion, uncertainty and a sense of being left to manage alone, which prompted their search for informational and psychological support.

> “My consultant came to the ward, said, you've got this problem, it's not curable, here's some meds, and then walked out again. And I … literally never saw him again.” [P3]

> “I was very confused by the whole diagnosis. I really didn't understand it, and I didn't feel like the doctors didn't necessarily explain it very well to me either.” [P1]

Participants also described a need for accessible information about IIH and what the diagnosis might mean for their future. In this context, joining was framed as a way of increasing knowledge and making sense of a condition that had previously been poorly explained.

> “And it was just to get more information really… because there’s not a lot out there. And when I got the diagnosis, I had a consultant I’ve never seen in person either, and the phone calls have been not very long at all, and so I didn’t really know anything about it…” [P7]

Seeking connection

Alongside informational needs, participants described a strong desire to meet others with similar experiences of IIH. Joining was often motivated by a wish to reduce isolation, feel understood and find a space where the emotional and condition-related consequences of IIH were recognised by peers.

> “I felt so alone. I felt isolated… my family were wanting answers, and I couldn’t explain it… when I joined Hope and realised that I wasn’t alone. That… was what was so important to me.” [P3]

> “…to be around people who are going through the same thing is really beneficial.” [P7]

Usefulness of a digital format

For some participants, the accessibility of a digital, self-paced format was itself part of the reason for joining. This was especially relevant where disability, limited mobility or fluctuating symptoms made conventional face-to-face support difficult to access or sustain.

> “I don’t get out of my house very much… support groups… don’t always necessarily work… Something I really, really liked about this course is it was, like, kind of self-led in my own time… But then also the fact that I could have that community of people with the same conditions as me… in this online hub was really, really useful.” [P2]

Learning self-management tools and regaining control

Participants also enrolled following recommendations from the IIH UK charity in the hope of gaining psychological tools to manage symptoms, mood, fatigue and wider life changes associated with IIH. Several described this as part of trying to regain a sense of control after feeling overwhelmed by symptoms.

> “I think I was losing hope… you get… passed from pillar to post… and then you get frustrated, so you have to take control of what you can take control of… and so I joined the IIH charity… they said, ‘try this.’ So, I went… well, you can’t go wrong really, can you?” [P4]

> “I think I probably thought …it’s going to help me better manage my symptoms, whereas more, it’s helped me mentally, it’s helped me mentally deal with my symptoms…” [P6]

> “I was dealing with a lot, like, depression and anxiety at the time… I needed new coping mechanisms… trying to build those new skills in the context of my health conditions now.” [P2]

Acceptability

The acceptability findings are organised around the seven TFA domains.

Domain 1: Affective attitude - the affective response of an individual towards the intervention

Relief, hope and peace

Participants generally expressed positive feelings about the Hope Programme, often describing relief, hope, peace, inspiration, gratitude and the value of feeling less alone after unsatisfying NHS experiences. These positive responses were most evident among completers, but some non-completers also described feeling inspired and more positive. This suggests that benefits could emerge even with limited engagement with the programme. For some, participation represented a shift from isolation and fear towards connection and a more hopeful view of life with IIH.

> “I think it's in the name, almost. It helps you build that hope back in your life, that. this condition isn’t, like, a be-all end-all for you type thing. Like, you can live with this, still have positive, healthy aspects of your life. still have relationships with other people. still do things that maybe you did do before, just in a different way.” [P2]

> “I think... I think it... it was relief, and that sounds really stupid, but. Hmm. I just think I wasn’t alone.” [P3]

> “I felt like part of a group of people who actually understand what it's like and so then I felt at peace with everything.” [P8]

Inspiration

Several participants reported feeling inspired to take a more active, positive approach to managing IIH and life goals (e.g. weight management, staying in work), sometimes linking this to symptom remission.

> “I think it helped inspire me to start taking a positive approach to controlling my situation as much as I can and therefore ultimately led to me being in remissions.” [P11]

Disappointment

Negative or ambivalent affect was less common, but when it was expressed it tended to relate to particular delivery features. Some participants described disappointment when Hope Cafés were poorly attended.

> “They [Hope Cafés] weren't particularly well attended... generally there might only have been 2 of us talking... which kind of makes conversation difficult... but you can't force people to talk.” [P5]

Domain 2: Burden - the perceived amount of effort that is required to engage in the intervention

Low overall burden and flexible

Most participants described the burden of engaging with the Hope Programme as low. They emphasised ease of navigation, the ability to work at their own pace and the flexibility to fit participation around work, family life and fluctuating symptoms.

> "I could just do it at night-times, where I'd just be sat down watching telly, or... take time out and do it whenever I had my own time... I think it was really easy to navigate and really well run as well." [P6]

> "I think there was not much effort required and we were given extra time to complete. It was ideal to accommodate within life management." [P9]

Cognitive and emotional burden

Some participants described the cognitive burden associated with screen-based engagement and the emotional intensity of the content. One participant suggested that some of the information should be delivered via podcasts to help with accessibility issues.

> "I did find... obviously, IIH is linked to vision issues. So... struggling sometimes to stay on the laptop to watch everything and really digest it all... I would suggest maybe, like, a podcast... because of that particular issue." [P1]

> "Attending the sessions, working through the material, discussions with other participants, it was doable spending a few hours a week... The sessions were in depth and I did feel mentally and sometime emotionally drained afterwards." [P10]

Volume of content

A further aspect of burden concerned the volume of material relative to the cognitive and energy limits of living with IIH symptoms. While flexibility helped to offset this, a participant did describe the programme as feeling dense or checklist-like at times.

> "It did feel like... a checklist. Which, when you're unwell, obviously isn't... isn't maybe the best thing... it's a lot of information to digest…. but the fact that you can break it up and do it in your own time, is the good thing, you know" [P1]

Domain 3: Ethicality - the extent to which the intervention has good fit with an individual's value system

Respectful and non-judgemental discussion of weight

Participants felt that the Hope Programme addressed sensitive issues such as weight, in ways that they experienced as respectful, non-judgemental, which aligned with their values. Participants contrasted the Hope Programmes approach with prior clinical encounters in which they had felt blamed, or reduced to their body size, rather than being seen as whole people. Participants emphasised the importance of self-compassion, boundaries and acceptance. Participants valued that weight was discussed in a balanced and compassionate way rather than being framed as the only meaningful issue in IIH care.

> "... I think how weight was mentioned throughout was, like, the right amount... it was written well... because... the first few things in my consultation, my consultant said to me was, like, lose weight, and then that was the only conversation he's ever had with me." [P7]

> “Yes, I feel very passionately about the weight stigma... If you want to help people lose weight, you have to do it from a nonjudgmental and compassionate standpoint... This is often completely missed by clinicians and often they come across as out of touch and often unkind.” [P8]

Emphasis on self-compassion, boundaries and acceptance

Participants also valued the Hope Programme’s emphasis on self-compassion, listening to their bodies and setting boundaries. This was important because it challenged prior experiences of self-blame, striving to restore a pre-IIH self and letting IIH define who they were. The Hope Programme helped participants focus on acceptance and taking control.

> “I gained... a massive understanding on how to connect to myself... boundaries was a massive one as well... having the boundaries to heal and the skills to listen to yourself and your body was the one big thing I took away.” [P1]

> *“It was not going to define who I was*.” [P5]

> “You have to take control of what you can take control of... going to an IIH Hope course... it's about acceptance... and what you can control.” [P4]

> “I liked the stuff on self-care the most, accepting this is the situation and being kind to ourselves about it.” [P8]

Domain 4: Intervention coherence - the extent to which the participant understands the intervention and how it works

Understanding the overall purpose and scope of the programme

Most participants generally understood the purpose of the Hope Programme as helping them understand IIH, practise self-management, and connect with peers. Several joined the programme expecting primarily medical information or help with symptom control, but came to understand it more broadly as an intervention aimed at coping, adjustment and living well with IIH. Participants felt that the programme made sense once they experienced how its different elements fit together.

> “I think I probably thought it was, like... it's gonna help me better manage my symptoms... whereas more, it's helped me mentally... it's helped me mentally deal with my symptoms, if you know what I mean.” [P6]

> “It was to inform, and improve confidence …in understanding and managing the conditions.” [P10]

Clarity about how specific tools work

Participants also demonstrated coherence in how they understood particular components (e.g. pacing, “boom and bust”, goal-setting, fatigue management). They were able to explain how these tools were intended to help them manage.

> “Boom and bust... that was me. As soon as I felt I had a good day, I worked like I did when I was really well, and then it probably took me 3 days to recover... that session 3 is the one I really need to go back to.” [P4]

> “Goal setting exercises really helped me to think about my goals but also break them into approachable steps to prevent them from being overwhelming.” [P11]

Domain 5: Opportunity costs - the extent to which benefits, profits or values must be given up to engage in the intervention

Reallocating discretionary time rather than giving up valued activities

Most participants reported low opportunity costs. They generally did not describe giving up valued activities or roles to participate, instead they described reallocating discretionary activities and time such as television time or evenings or lunch breaks. Several participants described making small adjustments to their routines to engage in the programme.

> "So, I used to work from home... So, I basically... did it through my lunch hour... I didn't really want to do it after work, I wanted to do it at a time when I was already on my laptop." [P1]

> "I did sometimes have to give up things in the evening, like maybe if I had some relaxation time, maybe that would be reallocated towards the course, but I think... because it wasn't a forever thing, it was manageable." [P2]

> "Actually, I think it was really good because, um, you know, I was working at the time... I just arranged my diary around it... I felt happier, because I was taking control." [P4]

Higher opportunity costs for synchronous elements (Hope Cafés)

The main opportunity cost mentioned was difficulty attending live Hope Cafés during working hours. Participants suggested running Hope Cafés more frequently in the evenings and at weekends.

> "I only attended one of the Hope Cafés... because it was in working hours... there was only one that I could attend, and it matched on my lunch break." [P7]

> "I couldn't attend any of the group sessions, which I feel sorry about as would have been good to talk and meet with others." [P9]

Domain 6: Perceived effectiveness - the extent to which the intervention is perceived as likely to achieve its purpose

Understanding IIH and feeling less alone

Participants described the Hope Programme as helping them make sense of IIH and feel less isolated. These accounts were shared by completers and non-completers, which supports the view that the informational and relational benefits were felt even by some of those who did not fully engage.

> "I'm really pleased it was there as essentially I felt less alone and that helped me a lot... I'm glad that the programme exists as it does provide **hope** for people." [P8]

> "It helped me a lot especially knowing other people were going through the same situation as me... It made me more motivated and educated me more on what I could do daily..." [P14]

Some participants continued to stay in touch with each other after the Hope Programme ended by joining WhatsApp groups

> "…there was a WhatsApp group that a few people had created as well. I think it carried on for a few… good few months afterwards, so that was nice to still kind of connect with a few other people and stuff like that." [P2]

Psychological coping and broader life impacts

Perceived effectiveness was not limited to IIH-specific knowledge. Participants described broader benefits for emotional wellbeing, trauma-related healing, work functioning, anxiety and coping with panic and claustrophobia.

> "I think it helped me... in terms of past trauma... boundaries... connecting to myself again... which helped for my healing." [P1]

> "It's meaning that I can stay at work... using the techniques... I get there... I don't think I'd be where I am today if I hadn't done the Hope course... it's helped me... one, come to terms with what I've got, and learning how to live with it. And not letting it rule my life." [P3]

> "It helped a lot it helped me with how to cope with different situations especially with work." [P15]

> "It doesn't just help cranial hypertension, it helps other bits as well... my biggest takeaway... has got nothing to do with [IIH], but... it definitely works for claustrophobia and panic on the tube." [P5]

Use of self-management techniques

Several participants, including non-completers, described lasting benefits from specific self-management techniques taught in the programme, including goal-setting, mindfulness, pacing, imagery exercises and self-advocacy in clinical encounters with one participant suggesting that the communication with health professionals be expanded to help prepare participants with difficult conversations around weight. These accounts suggest that effectiveness was often linked continuing to use particular self-management tools over time.

> "Goal setting exercises really helped me to think about my goals but also break them into approachable steps to prevent them from being overwhelming." [P11]

> "Well, interestingly, it's actually helped quite a lot... there was one very specific part... it was about putting your anxiety on a leaf and letting it go down the river. Such a simple concept. I can't begin to tell you how useful that has been... That was absolutely my biggest takeaway... it definitely works." [P5]

> "I'm very aware of the boom and bust, because, you know, it's about acceptance. I'm not the person I was before" [P4]

> "I've mainly used pacing and energy-management strategies, such as breaking tasks into smaller steps and resting before symptoms escalate. I've found these helpful in preventing flare-ups and managing fatigue…" [P13]

> "Talking about how to manage stress helped me the most…" [P16]

> "It was informative and gave some good coping strategies... I use mindfulness and pacing, I have used self- advocation in medical appointments which with better knowledge helped with my care." [P10]

> "It might be good to have something about medical gaslighting by doctors, about the focus on weight alone… Talking about medical access routes for getting the right diagnosis, support, and/or medication or surgery etc – and understanding NICE etc so participants know what they should expect." [P10]

Peer support and validation

Many participants described the value of peer support and validation, which again was evident in both completer and non-completer accounts. Feeling understood by others with IIH was a key mechanism of benefit, particularly when they found friends and family difficult to talk to because of their lack of understanding.

> "But they relate to it, so we don't have to go through everything that... because… you're in a room with the people who have what you have." [P5]

> "Yeah, it was... it was the support. I wouldn't have understood the illness as much... and it really helped me gain confidence in myself and advocate for myself, in certain situations that I probably wouldn't have, if I didn't take the course." [P1]."

> "The community aspect is something I saw at the very beginning...now I'm a member of IIH…so it was…Hope building" [P2]

> "I don't really talk to my family and friends about this, and I know a lot of people are the same, because they just don't understand." [P5]

For some participants, benefits were not immediate, but emerged gradually over time, particularly as participants revisited intervention materials and integrated their learning into their lives.

> "If I'm going to be completely honest, at the time, I didn't feel much of anything… I think as time has gone on, I felt more of that benefit from things, and especially because with resources from the course… you can look back at them." [P1]

Domain 7: Self-efficacy - the participant's confidence that they can perform the behaviour (s) required to participate in the intervention

Confidence in completing the programme

Self-efficacy for engaging with the Hope Programme was generally high. Participants described that the modular, bite-size, structure, clear navigation and self-paced format made the programme completion feel achievable, even when they had initial doubts. Participants' confidence grew once they started using the platform.

> "Yeah, I think because it was, like, in little individual sections, it wasn't too overwhelming, because it wasn't just one big section… like a lot to complete all at once, and because you can do it in your own time, and it was just broken down into little sections, I think it was quite easy to complete that way." [P6]

> "Once you'd kind of worked your way around the site, you kind of knew what you were doing… it was relatively easy to understand. There wasn't anything that jumped out at me that it'd be particularly difficult for somebody to... do that wasn't maybe computer literate." [P3]

More personalised, engaging information and activities

Some participants wanted more personalised information and more interactive features to improve engagement.

> "It wasn't very personalised, it would be very good if it was more interactive." [P12]

> “I feel that the sharing of reflections and goals could be made more engaging and somewhat more attractive for people to complete it.” [P9]

Symptom-related reasons for stopping using self-management tools

Some participants stopped using the self-management tools for positive reasons, such as feeling better, whereas others stopped using them because of the sensory and cognitive demands of participating while experiencing IIH symptoms. One participant found the reflective diaries daunting.

> “To be honest I have stopped using quite a lot of the strategies as I have gotten loads better, I am just taking life one day at a time although I obviously still have some bad days.” [P14]

> “Now the pain is so bad again as it’s back with a vengeance I’m no longer in remission so many of my tools go out the window and I feel so overwhelmed I can’t cope.” [P8]

> “At the time... my IIH was the most severe, so I was really struggling with things like reading... I used a screen reader a lot of the time... video was a bit easier... it was more imagery... easier... in terms of brain fog.” [P2]

> “I didn’t find the diaries helpful due I was never good to keep a diary… I stopped using diaries as I just find them daunting.” [P9]

Discussion

This study provides promising, preliminary evidence that the Hope Programme for IIH is both acceptable to participants and associated with sustained improvements in positive mental wellbeing. The acceptability findings provide some evidence for the mental wellbeing improvements, with participants gaining the knowledge, skills and confidence to use self-management tools and greater acceptance and self-compassion.

Mental wellbeing

Session 1 mental wellbeing in our sample was substantially lower (mean 18.2) compared with national SWEMWBS norms for women (mean 23.2), with nearly three-quarters (73%) scoring in the range indicative of probable/possible depression/anxiety. The mean mental wellbeing score of the IIH participants is the lowest of all the long-term conditions groups H4C work with including Long COVID (mean 18.6), multiple sclerosis (mean 19.5), Polyendocrine Metabolic Ovarian Syndrome (mean 19.5), cancer (mean 19.9), and musculoskeletal (mean 22.3).

Among 41 participants with repeated, matched outcome data, ≥1 point improvements were evident by midpoint (T2), increased further by programme completion (T3), and then remained stable at long-term follow-up (T4), with no significant differences between T2, T3, and T4. The pattern of change over time is informative showing that the intervention may help participants achieve early gains in mental wellbeing.

It is important to note that even the largest mean 2.2 improvement in mental wellbeing, which occurred between Session 1 (18.2) and Session 6 (20.4), indicated that the participants' mental wellbeing is still below the general population norms (23.2). This shows that mental wellbeing is low in people living with IIH and may possibly require further, higher intensity, mental health support.

The long-term improvement in mental wellbeing finding is broadly consistent with Coventry University's earlier long-term self-management evaluation. In an uncontrolled, follow-up of the in-person Arthritis Self-Management Programme, participants reported sustained benefits 8 years after completion in self-efficacy, psychological wellbeing, pain, fatigue, cognitive symptom management and communication with physicians, despite expected declines in physical functioning over time (Barlow et al., 2009).

By the end of the programme, the proportion of participants classified as probable or possible depressed/anxious had fallen from 73% to 56%. The proportion classified as well increased from 27% to 44%. This pattern was still evident at long-term follow-up, although the improvement had reduced slightly. This suggests that the programme may support both reduced psychological distress and improved positive wellbeing. Positive psychology is interested in the full range of human functioning and has the dual aims of alleviating psychological distress and promoting positive well-being (Seligman et al., 2006). These findings are encouraging and support our decision to draw on positive psychology theory and practice to develop the Hope Programme.

Qualitative findings

Reasons for joining

Many participants joined the Hope Programme because of negative experiences in clinical care. Many described poor communication at diagnosis, a lack of clear explanation about what IIH is, and a sense of being left to manage alone. The Hope Programme appears to have helped participants fill informational and emotional gaps that routine clinical services

were not consistently meeting. Some participants described increased confidence in self-advocacy, including in medical appointments after attending the Hope Programme.

Our findings are consistent with a study by Abbott et al. (2023) and Moes (2026), which found that people with IIH often experienced unclear, reductive, or stigmatising communication from health professionals, particularly around weight management. Moes (2026) research, which captured the experiential knowledge of 563 people living with IIH across 37 countries, described how clinical focus on weight loss causes people to feel devalued by medical professionals and that framing weight as the primary “cure" generates a "curative fallacy" that imposes an "impossible bind" of internalised shame and blame when symptoms do not resolve. Moes (2026) suggests that the IIH “treatment paradigm” where weight is considered a moral failing could partly explain the elevated levels of psychological distress in people with IIH. It is reassuring to see that participants on the Hope Programme valued the respectful and non-judgemental approach to sensitive topics such as the adapted IIH weight resources.

Acceptability of the Hope Programme

The qualitative findings help explain why the programme may have had an effect on mental wellbeing and broader self-management outcomes. Participants described the Hope Programme as one of the best things they had done. They valued the opportunity to connect with others who understood IIH, and reported benefits including feeling less isolated, and having a greater acceptance and understanding of their IIH symptoms. Some participants were reluctant to overburden their family and friends with their problems. Self-management researchers have explored how less intimate support, described as “weak ties” can be helpful in managing long-term conditions (Rogers et al., 2014). Weak ties are considered less stressful and may even be more durable and sustainable than stronger family ties (Rogers et al., 2014). This may be because reciprocal support among peers with a shared experience, such as IIH, may be less threatening to notions of being a burden and feelings of shame and guilt associated with disclosing to close family members and friends. The strength of the weak ties formed on the IIH Hope Programme was evidenced by the ongoing support participants sought after it ended by joining WhatsApp groups. We are aware that several online groups were set up to provide ongoing peer support and 65 participants have joined our Hope online community for continuous intervention content access, peer-support and self-management activities. This is noteworthy as ongoing contact could be important for boosting or sustaining self-management outcomes (Harrison et al., 2011). Positive initial group experiences have been linked to willingness to maintain contact with others (Harrison et al., 2011). The kindness and compassion, including self-compassion, experienced and practised by participants, have the potential for being helpful for improving mental wellbeing.

Participants coped more effectively and continued to use self-management tools such as goal setting, pacing, cognitive reappraisal, relaxation and mindfulness, many months after the Hope Programme ended. Within the TFA domains, the strongest evidence appeared in the domains of affective attitude and perceived effectiveness, while burden and opportunity costs were generally low because the asynchronous digital format enabled participants to engage flexibly around fluctuating symptoms. The Hope Programme’s asynchronous, digital format was useful for participants living with pain, fatigue, visual symptoms, work demands and caring responsibilities, because it allowed engagement at a time and pace that suited them. These findings were most clearly represented in the accounts from completers, however some of these benefits were also evident among participants who only completed 1 to 2 sessions. This is important as people living with fluctuating IIH symptoms may struggle with sustained engagement over the full six weeks duration. It also supports a more nuanced understanding of adherence and engagement and their association with positive outcomes in digital health (Torous et al., 2020). Partial engagement is the modal pattern across digital

mental health interventions, with average dose received of approximately 60% in the broader literature (Forbes et al., 2023). The figure of 76% (344/454) of participants attending at least 3 sessions exceeds digital intervention adherence benchmarks (Forbes et al., 2023).

Suggested improvements to the Hope Programme

The findings identify important areas for refinement of the Hope Programme. Although the burden of taking part in the Hope Programme was generally low, some participants described cognitive overload, visual strain and the amount of effort required to process large amounts of screen-based content. These observations are important in a condition associated with visual disturbance, headache, fatigue and brain-fog-like symptoms. The recommendations emerging from participant feedback, such as more audio content, careful review of content volume, and further attention to accessibility, should therefore be considered for future adaptations of the Hope Programme. Live Hope Cafés were valued by some, but attendance was harder during working hours and may need more flexible and equitable scheduling such as evening and weekend sessions. Finally, some participants suggested adding more content on navigating healthcare, self-advocacy, and managing experiences of dismissal or "medical gaslighting" in IIH care.

Strengths

A key strength of this study is that it evaluated the Hope Programme for IIH under real-world conditions, using a pragmatic multi-method design that combined longitudinal mental wellbeing data with in-depth acceptability data. Although this study does not directly address the James Lind Alliance top 10 biomedical research priorities for IIH (Mollan et al., 2019b), it contributes to an important related area identified during the priority-setting process, which is the need to improve education for people living with IIH. The intervention is a theory and evidenced-based, co-produced digital intervention for people living with IIH, which is likely to have enhanced its acceptability and usefulness. Scaling up of the Hope Programme for IIH can make a useful contribution to the provision of accessible, digital support for people living with long-term conditions set out in the government's 10 Year Health Plan to build a health service fit for the future (Department of Health and Social Care (2025).

The majority of self-management intervention research, and Coventry University's and H4C's evaluations of the Hope Programme for other long-term conditions (Anderson et al., 2017; Martin et al., 2019, 2020; Percy et al., 2024 Wright et al., 2021, 2022) have focused on immediate post-programme effects or short follow-up periods (e.g. 3-6 months). The present findings therefore make a useful contribution by showing that improvements in mental wellbeing and the use of self-management tools may be sustained for many months.

The acceptability analysis is also a methodological strength. Using the TFA enabled a more focused and in depth understanding of why the programme appeared to work well for many participants. Rather than just measuring satisfaction, the TFA provides practical and actionable information about what made the programme effective and where changes are needed to ensure it meets the needs of participants.

Limitations

This study has several limitations. First, this was a pre-post evaluation without a control group, so improvements in mental wellbeing cannot be attributed definitively to the intervention. Although the maintenance of improvements over time is encouraging, alternative explanations remain possible, including natural adaptation, regression to the mean, selective retention of those who benefited most, or the influence of other treatments and other factors over the follow-up period. Second, the outcome analysis was based on a relatively small subgroup of participants who completed SWEMWBS at all time points. This

raises the possibility of attrition bias, as those who remained engaged enough to provide follow-up data may differ systematically from the wider group of participants who enrolled. All participants classed as completers had done all six sessions of the Hope Programme. Our own internal audit data of our other Hope Programmes for long-term conditions (including IIH) show that approximately 50% of participants complete all six sessions. This study's inflated six session completion figure is also an artifact of the study design, in that we only followed up participants who completed the SWEMWBS in Session 1, Session 3 and Session 6. Four hundred and fifty-four participants started the Hope Programme, but only 83 completed mental wellbeing measures during the programme at all three internal time points and 41 completed long-term follow-up at 12 to 50 months, meaning that the long-term findings should be interpreted cautiously as these reflect a selected motivated subgroup of participants who may not be reflective of the larger enrolled cohort. It is worth pointing out the study sample (n=41) did possess similar characteristics to the larger cohort (n=454) with respect to age, ethnicity, IMD and mental wellbeing scores in Session 1 (data not shown). The 16 participants who provided qualitative feedback about their experiences tended to be slightly younger than the study sample (38 vs 42 years) at the point when they attended the Hope Programme and fewer were from the lowest 3 IMD deciles (27% vs 38%). Third**,** the study sample was demographically narrow. Nearly all the participants were women and White. While this may partly reflect the IIH population, it limits confidence about transferability to more diverse populations and highlights the need for more inclusive recruitment strategies in future studies. Fourth**,** the qualitative sample may also overrepresent more positive experiences. Most of the in-depth qualitative feedback was provided by programme completers, whereas non-completers contributed only brief written responses. Future studies would benefit from purposive sampling of participants with mixed levels of engagement to better understand what limits adherence.

Implications and recommendations for research and practice

A review of eight IIH audit standards covering eight NHS trusts showed gaps in key areas, including in Standard 5 (Holistic Care), where psychological support was absent in seven trusts and was significantly below compliance target in one trust (MacKeith et al., 2026). In a condition where routine clinical care focuses primarily on medical monitoring and symptom control, the Hope Programme has the potential to fill this gap by providing a scalable self-management intervention to improve mental health.

For research, the next step should be a prospective clinical and cost-effectiveness randomised controlled trial (RCT) and include a more diverse sample. It would also be useful to examine mechanisms of change more explicitly, for example whether mental health and wellbeing improvements are mediated by increased self-compassion and self-efficacy, greater understanding of IIH, or sustained use of CBT techniques and other self-management techniques such as pacing and mindfulness. Future studies should also address implementation questions. The present evaluation suggests that a charity-licensed, peer-facilitated model may be feasible and acceptable, which has clear implications for reach and scalability if effectiveness is confirmed. However, implementation into clinical pathways would require attention to facilitator training, governance, digital inclusion, referral routes, and how best to integrate peer-led self-management support within specialist IIH services.

For practice, the digital and asynchronous format appears especially suitable for IIH. Participants reported low burden and opportunity costs overall and valued being able to engage at their own pace, which is likely to be important in the context of headache, fatigue, cognitive difficulties, and visual symptoms. The findings also indicate areas for refinement, including managing cognitive load and visual strain, reviewing the amount of content, and

considering how to support optional synchronous elements such as Hope Cafés for those with greater symptom burden or competing commitments. Co-creating and testing a self-directed version of the Hope Programme for IIH would increase participant choice and accelerate scaling and reach.

Conclusion

The Hope Programme for IIH has been delivered by people with lived experience to 454 participants. This evaluation provides promising early evidence that the Hope Programme for IIH is a highly acceptable digital self-management intervention that may support meaningful and sustained long-term, improvements in mental wellbeing. Participants valued its flexibility, peer support and IIH specific content. Many participants continued to use the self-management tools in the long-term.

Although the findings require confirmation in a randomised controlled trial with a more diverse sample, they indicate that a co-produced, peer-supported digital intervention may help address an important gap in holistic support for people living with IIH. For many, the programme addressed unmet needs that had not been met by the NHS. The findings suggest that the Hope Programme supports psychological, emotional and behavioural adaptation among people living with IIH.

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Appendix 1 - Interview schedule

Opening and context

- What made you interested in taking part in the Hope Programme?

TFA Acceptability interview schedule example questions

The following are examples of open-ended questions designed to elicit qualitative data for each of the seven TFA constructs:

TFA Construct	Description	Example interview questions/prompts
Perceived Effectiveness	The extent to which participants believe the intervention is likely to achieve its intended purpose.	How well do you think this intervention helped/will helped you achieve [specific goal, e.g., manage your condition, change a behavior]? What specific aspects made you feel it was working (or not working)? Were there particular modules, tools, or exercises that you found especially helpful or unhelpful? What made them so? Have you taken anything from the programme that you are still using, or plan to keep using, in your everyday life?
Affective Attitude	How participants feel about the intervention (e.g., "liking", "disliking").	Overall, what are your feelings or reactions to the Hope Programme. What aspects, if any, did you particularly like (most/least) or dislike? How does the Hope Programme compare to anything else you may have tried?
Burden	The perceived amount of effort (physical or mental) required to participate in the intervention.	How much effort did you feel was required to learn to use the platform. How much effort was it to engage with the intervention components (e.g., attending sessions, using a toolkit, tracking information)? Did any part of the intervention feel particularly challenging or difficult to manage? E.g. Ease of navigation

Ethicality	The extent to which the intervention is considered morally acceptable and right.	Did you have any concerns about the fairness or morality of how the intervention was delivered or who it was offered to? Were there any aspects that felt intrusive or made you uncomfortable? Did you have any ethical concerns with the intervention?
Intervention Coherence	How well participants understand the intervention and how it is expected to work.	Could you describe, in your own words, how the Hope Programme was supposed to help you? What was the purpose of the intervention in your opinion? Did everything about the process make sense to you?
Opportunity Costs	The benefits, profits, or values that must be given up to engage with the intervention.	Were there things you had to stop doing, or time you had to give up, in order to participate in this intervention? Do you feel the time and resources you put in were worth the potential benefit? How much of a priority was it for you to engage with the intervention?
Self-Efficacy	Participants' confidence in their ability to perform the behaviors required to participate in the intervention.	How confident did you feel about your ability to complete all the tasks involved in the intervention? Did you feel you had the necessary skills or support to engage fully?

Appendix 2 – Additional quotes

Domain Theme/ TFA domain name	Quotes
Reasons for joining	“And you’re very much left on your own… The NHS is pretty poor at treating us… So I just thought, well, I’ll give it a go and see what I get out of it.” [P5] “Um, I… I didn't have any expectations in… it was going to help me with my IIH as such. I was hoping it was going to help me understand my IIH. And that's when… when… I was still really struggling to understand it when I came across. the Hope course. Um… I wasn't, um… seeing my neurologist very often, he didn't really explain things. So, I just wanted to understand the condition and That's what I… that… that was the goal of attending the Hope course, was understanding IIH.” [P3]
Affective attitude	"I do believe that the Hope Programme was one of the best things that I did… and if I get the chance to meet anybody with IIH, I will ask them whether they have done the Hope Programme and encourage them to do so." [P3] "It’s an amazing programme… It’s really helped me, and I can’t see it not helping other people.” [P3] “I’m really pleased it was there – essentially I felt less alone and that helped me a lot… I’m glad that the programme exists as it does provide hope for people.” [P8] “I really liked the Hope Programme and have recommended it to other people, I was glad I participated.” [P10]
Burden	“I could just do it at night-times, where I’d just be sat down watching telly, or… take time out and do it whenever I had my own time… I think it was really easy to navigate and really well run as well.” [P6] “I do feel like it was a lot of work but it was all worth it as I felt like I was doing this alongside others.” [P8]
Ethicality	“The idea of self-compassion... these are all things I remember really just struggling with and still honestly do. But... it was that initial boost... ‘it's okay to put myself first’... I need to do this for myself, this is important.” [P2] “That’s what keeps me on the straight and narrow, is being in charge of what I’m doing, rather than the IIH being in charge of me. And that’s absolutely key for me.” [P5]
Intervention coherence	"I think the expectations probably were… one, it was being run by people who have experience in running these kinds of courses… two, I would be put in contact with other people who have my condition… and… it has given me tools that I can pull out when I need them." [P4]

	“I quite like that you could see other people’s comments on there, which sometimes meant that I did it a bit later, so I could see them, or there’d been more on that. And I liked how you can integrate on the… like, it wasn’t a social media page, but it feels like that, like on the newsfeed sort of thing, doesn’t it? I quite like that element, because I sometimes struggle with online learning, but that felt a little bit more interactive than an online session.” [P7]
Opportunity costs	“I work full-time… sometimes had to miss work for other programmes, which meant I had to catch up later…I was able to say, okay, I feel up to doing this right now.” [P2] “I think there was not much effort required and given extra time to complete. It was ideal to accommodate within life management... Absolutely feel that it worth the effort” [P9]
Perceived effectiveness	"Like I said, I think with… journaling… that’s helped me massively… the mindfulness and the breathing techniques as well… I do use, which I do find quite helpful… and, like I said, just getting out in nature as well… just go for a little walk… then that just… lifts your mood." [P6] "I thought the Session 5 was interesting… we have changed the way we eat… I tend to make sure I walk to the office … that’s been really good… " [P5] "I do use mindfulness… I’d never heard of it before… I tend to use it when I’ve had a really bad day… I just need 5 minutes… that is just focusing on nothing but me, rather than everything else that’s going on around me." [P3] “The Hope Programme helped me understand IIH better and feel less isolated... While it didn't change my physical symptoms, it supported me emotionally and helped with coping and self-management.” [P13]
Self-efficacy	"To be honest, I was very nervous at first… I put a lot of pressure on myself that I kind of had to let go… which was good that the sessions started out with… self-compassion… because I think if that had come any later, that might have been more of a problem." [P2] "I think… I was okay… I needed to think a bit about the goal setting… I needed to think, because I wasn’t quite sure where I was at, and what goals I was going to achieve, but… I got there in the end." [P3] “At first I was a bit like, oh gosh, am I going to be able to do all this? But then once I started doing it and really enjoying it, it was fine... I'll easily be able to do it.” [P6]

Publication and use statement

This report was funded by an IIH UK research grant 2024.

The report presents findings from an evaluation of the Hope Programme for people living with Idiopathic Intracranial Hypertension. The programme was delivered in partnership by IIH UK and Hope 4 The Community CIC.

This report is intended for public sharing, including with people affected by IIH, healthcare professionals, researchers, commissioners, voluntary sector organisations, funders and policy stakeholders. It may be used to support service learning, quality improvement, research development, commissioning discussions and future funding applications.

The content may be shared for non-commercial purposes, provided that the report is cited appropriately and not altered in a way that misrepresents the findings, the programme, IIH UK or Hope 4 The Community CIC.

The findings presented in this report are based on evaluation data available at the time of writing. The report does not provide medical advice and should not be used as a substitute for clinical assessment, diagnosis or treatment. People living with IIH should seek advice from an appropriate healthcare professional about their own care.

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